

# DEPARTMENT OF HEALTH AND SOCIAL SERVICES DIVISION OF DEVELOPMENTAL DISABILITIES SERVICES

# GOVERNOR'S ADVISORY COUNCIL (GAC) TO THE DIVISION OF DEVELOPMENTAL DISABILITIES SERVICES

### **April 21, 2015**

The Governor's Advisory Council to the Division of Developmental Disabilities Services met on April 21, 2015, at the 1056 Woodbrook Conference Room, Dover.

**COUNCIL MEMBERS PRESENT:** Terri Hancharick, Chair

Thomas Rust

Timothy F. Brooks, Ed.D.

Angie Sipple

**COUNCIL MEMBERS ABSENT:** Jamie Doane

**STAFF MEMBERS PRESENT:** Jane Gallivan

Marie Nonnenmacher

Pat Weygandt

Vicky Gordy - minutes

GUESTS PRESENT: Vicki Haschak, Elwyn

Cathy Cowin, Christina School District

**CALL TO ORDER:** The meeting was called to order at 1:25 p.m.

**NEXT MEETING:** May 19, 2015 - 11:00 a.m.

**APPROVAL OF MINUTES:** The Council approved March 17, 2015 minutes once

announced changes are completed.

**ADDITIONS TO AGENDA:** Council Membership

## **Council Membership**

A person interested in becoming a member of the Council reportedly will attend the May 19, 2015 meeting. Another frequent guest of Council has shown an interest in possible Council membership. GAC currently has two available Council seats. Typically, there are representatives from each of Delaware's counties on the Council. Currently, no Council members reside in Kent County. Council members were requested to continue to seek for possible additional membership candidates that reside in Kent County.

### **Family Support Waiver (FSW)**

DDDS continues to utilize feedback from family groups to continue work developing the CMS application for the Family Support Waiver. Definitions will be readdressed with family group members that provided feedback. DDDS continues work surrounding developing Target Case Management (TCM) that supports the FSW. DDDS began work of the actual wording of the State Plan. The cost is being examined to include searching for long term resources. Terry Macy is working with consultant to develop the person centered planning process.

The plan will be submitted internally mid-May and submitted to Legislature no later than June 1<sup>st</sup>. DDDS continues to have concerns of receiving Legislature approval to move the FSW forward without additional staff to support. If the Legislature cannot support the FSW in FY16, readdressing in the future may be accomplished, as infrastructure will be sound. DDDS continues to look at all internal possibilities to create different processes that will allow staff to be used differently to reshape for other arenas. For example, DDDS has recently been re-examining respite to include developing an RFP for respite services to be contracted to free staff to utilize differently.

## **Supported Decision Making**

The last "being a REAL person" meeting was held on April 10, 2015. DDDS Director identified a small grant sponsored by the National Resource Center for Supported Decision-Making that would help this initiative. DDDS in conjunction with the Developmental Disabilities Council continues work to win grant. The work group is making headway in terms of legislative options to modify regulations for a better process and to define who and how supported-decision making can take place. Supported Decision Making is in lieu of guardianship where a person could designate someone to assist them in decision making (i.e. medication administration usage, personal finances, etc.). This is an alternative way other than someone assuming full guardianship. To have someone "officially assigned" provides status to the person for the individual to promote formalizing the process for doctor visits, banking, etc.

#### **DDDS Quality Working Group**

The Working Group is hoping to create an online web-based "report card" for families to evaluate provider agencies. In order to create "report cards" the Working Group needs to establish commonly agreed upon standards and outcome measures to provide overall rankings and individualized reports for specific services and homes utilizing a 1-5 rating scale (5 being the highest).

The Council reviewed the DDDS Quality Working Group report that was submitted to the Joint Finance Committee (JFC) on April 1, 2015. Page eight of the report reflects recommendations that include resources for project manager to facilitate and research, additional DDDS staff with an understanding of analytics to maintain the ranking system and to increase provider rates to 80% of the benchmark (based on rebasing DSP rate report). The increase to providers was recommended as system may take years to develop and Working Group was concerned no increase would be funded until completion of project.

The Working Group reviewed South Carolina's ranking system and recently DDDS has looked at a canned system that may be licensed as a "data setup". A few states have developed this type of ranking system, while more states are moving toward posting/publishing licensing standards/reports on websites for transparency. Reportedly, many states would like to pay for performance but CMS is a pay for service system; therefore, until CMS changes Home and Community Based Waiver programs rulings pay for performance is not feasible. Pay for performance is a possibility for states that moved toward managed care due to payment option flexibility. (DDDS is not suggesting moving toward managed

care.) Reportedly, during a recent conference call with CMS regarding future directions of long term projects, incentivizing payments was discussed.

### **Update on GAC Transition Groups**

As the oversight committee, GAC must keep focus on task. GAC determined that substitute Work Group members are not permitted although anyone may attend as "public at large". For the next Work Group meetings, name tents will be available for Work Group members. GAC will suggest to Work Group chairs to accept comments/questions of "public at large" during the end of the meeting. Day and Residential Work Group e-mails should be shared with GAC members.

DDDS will develop similar formats for both assessment tools that are easily importable to a data system. The working groups are providing input/recommendations concerning types of questions and evidence needed to prove compliance for the content of assessment. Other goals may be included in services although assessments must be based on service definition (service definitions should be available for work groups). For instance, an individual receiving Day Habilitation Services is not required to present an employment goal, which is reviewed during the planning process (not the assessment process). The essential life plan procedures and policies will be reviewed although not as an assessment of the actually site. This additional piece is the responsibility of DDDS. If the essential life plan, policy, or public law states employment must be offered as first choice, evidence supporting this may be questioned. DDDS continues to work to provide a robust planning process for individuals that live home with families.

The State of Delaware holds the responsibility to look behind once the provider self-assessments are completed. The predominance of other states methodology reveals that there is a provider agency self-assessment, an assessment by the individual receiving services and state performs a look behind assessment to compare data. This appears to be the trend. Over the long term, licensing will continue to assure provider agencies stay in compliance. Out of state agencies authorized by DDDS will be required to complete assessments.

The Council discussed how self-advocates may be best choice to complete the assessment with the individual who is receiving services. Once the U of D, Center for Disabilities Studies completes the National Core Indicators interviews, Council may invite team (including self-advocates) to report on impression of interview outcomes. Interviews with individuals who are non-verbal should be performed with the person who "speaks their language" and knows the individual well (i.e. family member, friend, direct support staff).

The designated chairs of each group are doing well. Day Service Work Group developed a timeline. Ground rules and documents are reviewed during meetings. Before the Work Groups initial meetings, the DDDS director met with some self-advocates and explained Work Group roles. The Council spoke how self-advocates require some coaching and Work Groups may need to slow down the pace of meeting if necessary. This adds value over the long term of the project. Both Work Groups identified self-advocates for co-chair. The idea of chairs and co-chairs of work groups discussing meeting before meeting occurs was discussed as a possibility by Council. GAC representative will speak to the chair of work groups to explain situation. DDDS representatives in each group are doing well following up with needed information.

A transcription services is transcribing recorded minutes from each meeting, therefore minutes from last meeting will be available before the next weekly meeting. Transcriptions are almost verbatim and costly. If Work Groups find minutes are not helpful, please advise DDDS.

Hawaii's (both day and residential) assessment tools were distributed.

## **How DDDS works with DART regarding Complaints**

Due to an individual's suspension from DART transportation to and from day services, GAC discussed DART's suspension policy. Reportedly, suspensions from DART appear to be at the discretion of the driver. There is no evidence as reported by DART that driver spoke to Elwyn staff and the individual's family was not aware of suspension until after eight days. Reportedly, after two or three warnings other individuals received suspensions from DART. The effects of this are many, as provider agency staff must provide transportation, which takes them from normal routine of providing services to others along with an additional cost. Parent is concerned as individual prefers for provider agency to transport and may display the wrong behavior in the future when DART privileges become reinstated.

The Council reported families have concerns regarding DART drivers receiving no medical training and the lack of punctuality without communicating to individual's family.

DDDS currently does not interface with DART as with other state agencies. Pat Weygandt, Director of Professional Services and Marissa Catalon, Director of Day and Transition Services will reach out to DART to inquire how DDDS and DART can build on working relationship and policy per Council's request.

#### **Joint Finance Committee (JFC) Hearings**

The Council discussed the DDDS Joint Finance Committee Hearing that occurred on March 26, 2015 (rescheduled due to weather). Someone testified regarding not agreeing with how DDDS allocates funding; more specifically, that high-risk individuals receive priority. This concern seemed to be tied into families beginning to plan for transition, which DDDS fully supports. DDDS feels that it is critically important to be the safety net for individuals served. DDDS will review the risk assessment tool and discuss the possibility of determining a specific age of parent that once reached automatically moves the individual to the next higher risk category. This may help families recognize that DDDS supports families planning for transition.

### **Reports from CMS Transition Plan Work Group**

This topic was discussed under "Update on GAC Transition Groups" above.

## **DDDS and DOE Working Relationship**

The Council discussed how to build a collaborative effort to provide a smooth transition for young adults from school to receiving DDDS services. The DDDS Day and Transition Unit has been present and reports to all informational sessions with the DOE. The addition of the employment navigators has provided support to DOE by assisting with applications and answering family's questions.

One of the challenging pieces is that children are placed out of state due to various reasons from DOE. DDDS is stopping this practice and has tried to intervene to stop this from happening recently. DDDS is aware that much work is needed in this area. Recently, DDDS reviewed all out of state placements and began process through the ICT to identify funding. Many unmatched resources are utilized for out of state placements. DDDS intends to focus on better services to younger individuals that are more "children friendly" as a future project to include creating settings more appropriate to keep youth in

state, close to families and educate appropriately. DDDS preliminary discussions have occurred that included developing a program, identify resources, employees to manage, etc. This is on DDDS agenda.

Frann Anderson has been very helpful and has volunteered to collaborate with University of Delaware Center of Disabilities Studies to develop training surrounding transitioning.

In an effort to help families navigate the DDDS system, DDDS supports connecting families and individuals with others in their communities. DDDS has almost completed developing a brochure surrounding family services to assist families understanding of available DDDS services. DDDS is working with Parent to Parent and Family Voices to make a community connection with other families once determined eligible. Self-advocacy groups are becoming stronger and are planned to be tied into process as well. DDDS is in the process of moving to targeted case management that will support DDDS goal of providing a more solid system.

The Council discussed that many families are not aware of options other than DDDS. Other Medicaid packages may be able to support individual's needs more effectively. If the expansion of financial and benefits counseling in every program occurred, it would enhance family's knowledge. DOE has an expectation that family support specialists help parents understand that they may choose to receive day habilitation services and supported employment services combined for family member. DOE reported that parents are struggling with concept as well.

## **Disability Policy Seminar (what's happening nationally)**

Terri Hancharick, GAC Chairperson attended the Disability Policy Seminar for three days in Washington, DC, where emphasis was on community. Terri reported all states are experiencing resistance with transitioning. Terri updated Senator Coon's staff regarding work Delaware, DDDS, and GAC is doing to transition to the community rule.

A father spoke whose son passed away a few years ago who said that what we did years ago was right and good; it's not right anymore.

#### **Announcements and Informational Items**

Nothing reported.

#### **Adjournment**

The meeting adjourned at 3:15 p.m.